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Will Your Advance Directive Be Followed?

A Report by the Robert Powell Center for Medical Ethics

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key conclusions

In the wake of the Terri Schiavo case, many authorities are urging Americans to complete advance directives. Every state authorizes these legal documents, which allow a person to specify whether and under what circumstances she or he wants life-preserving medical treatment, food or fluids when no longer able to make health care decisions.

However, the laws of all but ten states may allow doctors and hospitals to disregard advance directives when they call for treatment, food, or fluids. Increasingly, health care providers who consider a patient's "quality of life" too low are denying life-preserving measures against the will of patients and families – and the laws of most states provide no effective protection against this involuntary denial.

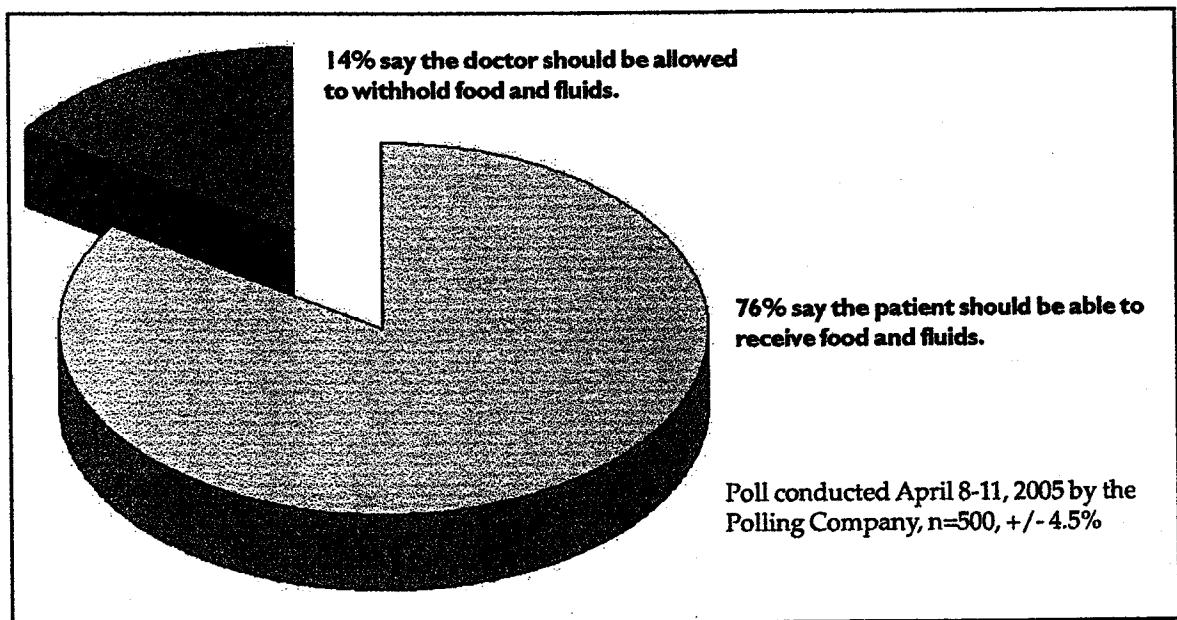
The result: in most states, if you want life-saving treatment – or even food and fluids – there is no guarantee your wishes will be honored, even if you make them clear in a valid advance directive.

Will Your Advance Directive Be Followed?

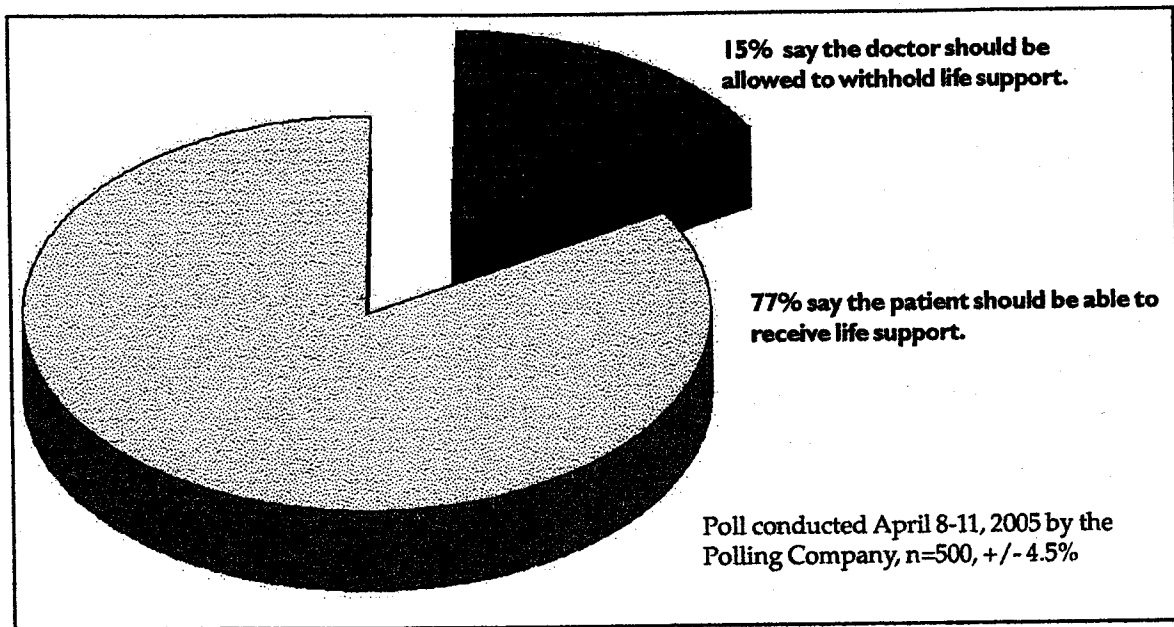
The Public Believes Patient and Family Choices for Life-Preserving Measures Should Be Respected, Even When Health Care Providers Disapprove

Americans overwhelmingly believe that when they or their families make the choice for food, fluids, or life support, those wishes should be respected – despite the contrary view of doctors who may think their quality of life too poor. A nationwide survey by the Polling Company, conducted April 8-11, 2005, found that by 76% to 14% the public believes that when a seriously ill patient has indicated he or she wants food and fluids, the patient's wishes should be respected even though the doctor thinks the patient's quality of life is too low to merit food and fluids.¹ By the similar margin of 77% to 15%, the public believes a patient's expressed desire for life support should prevail over a doctor's contrary view of the patient's quality of life.² (The public believes similar deference should be given to family over medical views when the patient's desires are unknown.³)

A desire for life-saving measures is common. A study published in the *Journal of the American Medical Association* (JAMA) found that 48% of a national sample of seriously ill patients in Veterans Administration hospitals wished to "use all available treatments no matter what the chance of recovery" compared to 31% who did not.⁴



* By 72% to 18%, they believe a family option for food and fluids should prevail over a doctor's view that the patient's quality of life is too poor; by a 74% to 15% margin, they believe a family option for life support should be respected.



Health Care Providers Are Increasingly Denying Life-Preserving Measures In Contravention of Patient and Family Directives Choosing Them

As has frequently been emphasized by commentators during and following the controversy over the Terri Schindler-Schiavo case, a legal document generically called an "advance directive"⁺ is the clearest way for someone to give directions concerning whether and under what conditions he or she would want food, fluids, or life-preserving medical treatment if no longer able to make and communicate health care decisions. The laws of every state and the District of Columbia, as well as U.S. territories, make provision for such advance directives.⁵

Increasingly, however, doctors and hospitals, often working through ethics committees, are asserting the authority to deny life-preserving measures against the will of patients and families – and implementing that authority in a growing number of cases. According to Dr. Lachlan Forrow, director of ethics programs at Boston's Beth Israel Deaconess Medical Center, "About 15 years ago, at least 80 percent of the cases were right-to-die kinds of cases. Today, it's more like at least 80 percent of the cases are the other direction: family members who are pushing for continued or more aggressive life support and doctors and nurses who think that's wrong."⁶

A study of policies at 26 California hospitals, for example, found that all but two of them specifically defined circumstances in which life-preserving treatments should be considered nonobligatory even if requested by a patient or patient representative. Commonly, they would deny treatment to patients with severe, irreversible dementia.

⁺ The term "advance directive" includes durable powers of attorney for health care, living wills, health care declarations and instructions, and other documents with titles that vary from state to state.

This would presumably include people with Alzheimer's disease. The authors of the study urged that health care providers "refuse to provide nonbeneficial treatment and then defend their decisions as consistent with professional standards."⁷

As one journalist has noted, this reflects "a turnabout in medical ethics, one in which doctors no longer want to employ all that medical science has to offer to keep patients alive and families find themselves fighting for their loved ones' right to live."⁸

A leading legal treatise lists 23 court cases that have arisen from conflict between patients and their family members who want life-preserving measures and health care providers who wish to deny them.⁹ The treatise authors note that "the development of medical professional standards about when it is appropriate and when it is not to provide life-sustaining medical treatment ... has been going on through the barrage of writings in the medical and ethical journals for more than a decade. More recently, formal efforts have been undertaken in a variety of places, with individual hospitals, groups of hospitals or other health care providers, and medical societies drafting 'futility guidelines.'"¹⁰

Two examples of such guidelines:

The Society of Critical Care Medicine's Task Force on Ethics issued a "Consensus report on the ethics of foregoing life-sustaining treatments in the critically ill" which maintains that *even when a patient requests a particular therapeutic treatment:*

If a requested treatment entails, according to the norms of medical practice, loss of function, mutilation, or pain disproportionate to benefit, the physician and nurses are not obligated to provide it.¹¹

The guidelines state, "Both preservation of life *and quality of life* must be weighed when making decisions concerning withholding and withdrawing life-sustaining treatments."¹² As one sympathetic medical commentator noted, under these guidelines, "Because treatment choices must be considered in relation to a patient's overall condition, a treatment offering a reasonable expectation of physiologic benefit may be withheld from terminally ill patients."¹³

The American Thoracic Society issued an official statement on "Withholding and Withdrawing Life-Sustaining Therapy" stating that life support "can be limited without the consent of the patient or surrogate when the intervention is judged to be futile." The paper defined "futile" as an intervention "that would be highly unlikely to result in a meaningful survival for the patient.... Survival in a state of permanent loss of consciousness...may be generally regarded as having no value for such a patient."¹⁴

In light of this, it is not surprising that a study published in the *Archives of Internal Medicine* in 2004 analyzing compliance with advance directives through a survey consisting of hypothetical cases found that the treatment decisions physicians said they would make were inconsistent with the patients' advance directives in 65% of cases. Among the factors more likely to influence physicians' treatment decisions was the doctor's perception of the patient's "quality of life."¹⁵

Denial of Care as "Futile" Is Often Based on "Quality of Life" Rather than Physiological Grounds

While denial of life-saving measures against the will of patients or family members is frequently justified on the grounds that the treatment is "futile," it is important to distinguish between the narrow physiological and the broader value-laden use of the term. As described by the New York State Task Force on Life and the Law, "Some physicians use 'futile' narrowly, considering treatments to be futile if they would be physiologically ineffective or would fail to postpone death.... Many physicians embrace a broader, more elastic understanding of the term. ... [A] treatment might be seen as futile if it does not offer what physicians consider an acceptable quality of life. For example, in one survey, a majority of physicians agreed that for a severely demented patient with Alzheimer's disease, CPR [cardio-pulmonary resuscitation] would be 'so clearly inappropriate or futile on medical grounds that physicians should be permitted to institute DNR status based on clinical judgment, without obtaining consent.'"¹⁶

One study, based on physician interviews, found that "Most often when futility arguments were invoked, they were used to support evaluative judgments based on quality of life considerations, only rarely to designate treatments that were medically inefficacious. Indeed, throughout the transcripts, physicians sought to frame value judgments as medical decisions."¹⁷

In 1991, the American Medical Association's Council on Ethical and Judicial Affairs criticized the use of this broader, "quality of life" view of futility to deny life-preserving measures against the will of patient or family:

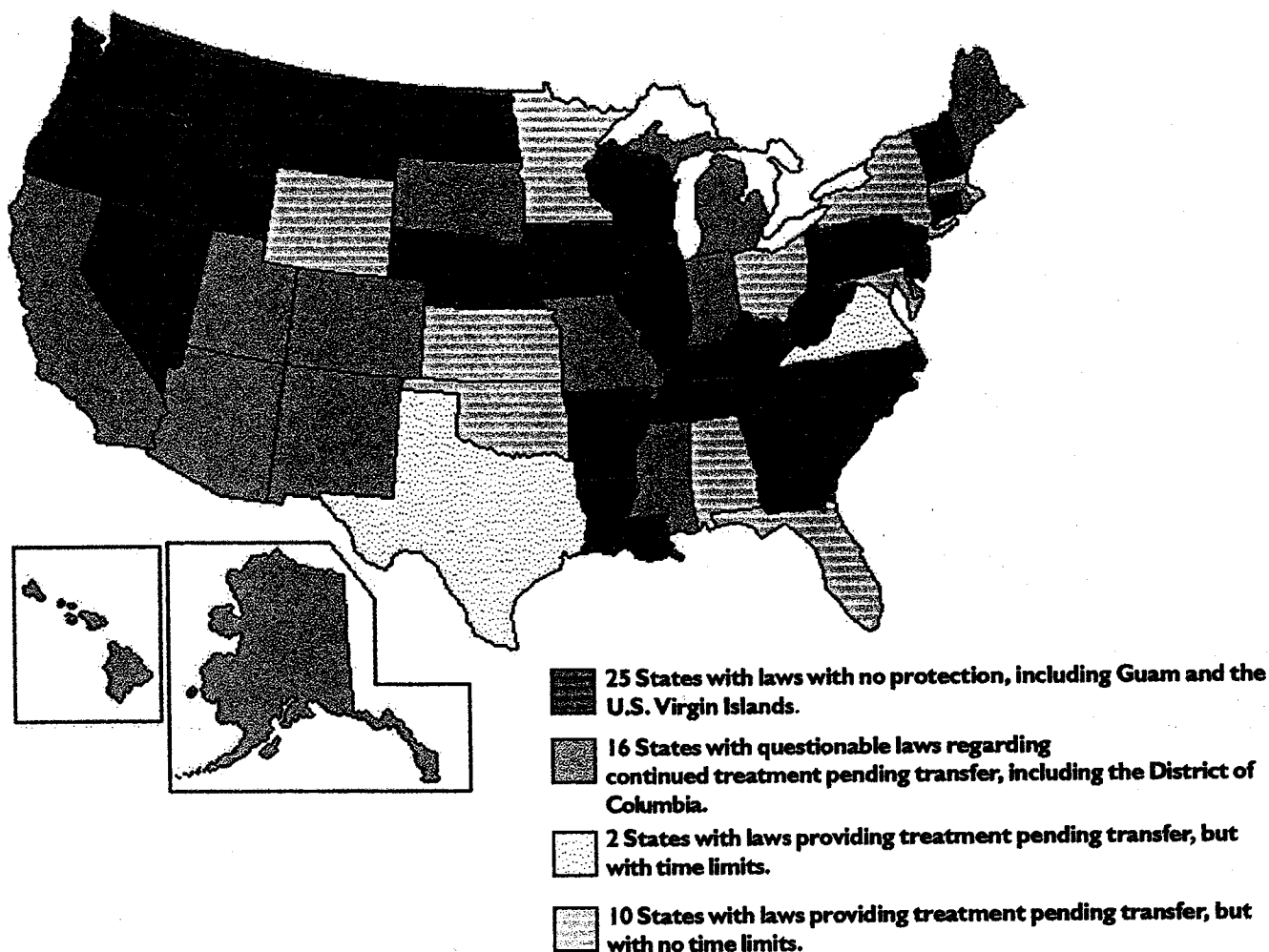
This approach to defining futility replaces a medical assessment (i.e., whether a reasonable potential exists for restoring cardiopulmonary function to the patient) with a nonmedical value judgment that is made by the treating physician (i.e., whether 1 day, 1 week, or 1 month of survival by the patient — perhaps in a severely debilitated state — is of value to him or her). This interpretation of futility is inconsistent with the principle of patient autonomy, which requires that patients be permitted to choose from among available treatment alternatives that are appropriate for their condition, particularly when such choices are likely to be influenced by personal values and priorities.

... Examples of some benefits that have been described as appropriate indications for CPR [cardio-pulmonary resuscitation] are a "meaningful existence" after resuscitation or an acceptable quality of life for the patient. These determinations, which attempt to define the types of treatment and the qualities of existence that constitute a benefit for the patient, undermine patient autonomy because they are based on the value judgments of someone other than the patient.

These judgments of futility are appropriate only if the patient is the one to determine what is or is not of benefit, in keeping with his or her personal values and priorities.¹⁸

It is noteworthy that the value judgments of physicians are frequently at odds with those of patients. For example, the JAMA study cited earlier that found that 48% of seriously ill patients wanted to "use all available treatments no matter what the chance of recovery," compared with 31% of patients who disagreed, also found that among physicians, only 7% agreed with the pro-treatment position, compared to 81% who disagreed.¹⁹

Most State Laws Fail to Protect Patients and Families Who Want Food, Fluids, or Life Support When Health Care Providers Deny It on Quality of Life Grounds



Only ten states have laws that essentially protect patients' directives for life-preserving measures.*

25 Unprotective Laws. The relevant laws of twenty-five states and territories provide no effective protection of a patient's wishes for life-preserving measures in the face of an unwilling health care provider.

Particularly striking is Connecticut's statute, which immunizes a physician who denies life support to any terminally ill or permanently unconscious patient; the physician need only have "considered the patient's wishes concerning the withholding or withdrawal of life support."²⁰

* Relevant provisions of all the states' laws, together with statutory citations, are provided in the appendix.

Most state statutes, in allowing health care providers to refuse to comply with a patient's advance directive for reasons variously described as ethics and judgments of medical inappropriateness, make some reference to providing an opportunity for the patient to transfer or be transferred to another, willing, health care provider. In some states, the unwilling provider must make a "reasonable" effort to bring about the transfer; in others, must simply cooperate with or not impede it. The critical point is that in these states there is nothing approaching a *duty to provide life-preserving measures while the patient is awaiting transfer*.^{*} It does the patient little good to be transferred already dead. It can by no means be assumed that unwilling health care providers will do so while the patient's family or others search around for another health care facility willing to accept and treat the patient. For example, representatives of Houston hospitals established a task force that developed a model protocol for denial of treatment in 1996. The protocol specified that if no transfer had been effectuated during a 72 hour period between notification of the family of the doctor's intent to deny treatment and an ethics committee meeting that ratified the doctor's position, treatment should generally be terminated promptly after the meeting. They wrote that they "firmly believe that professionals and institutions should not be required to provide treatments ... if patients cannot or will not arrange transfer."²¹

16 Questionable Laws. Sixteen states including the District of Columbia have statutes with language that might be cited to support a right to receive life-preserving measures specified in accordance with an advance directive, but either the language is ambiguous or it could be trumped by other provisions in state law.

Unlike the bulk of the states in the "unprotective" category, which merely give the patient the right to transfer from an unwilling provider, or at most require the unwilling provider to make a "reasonable effort" to bring about a transfer, five states⁺ specifically require an unwilling provider successfully to effectuate a transfer to a willing provider. This certainly suggests the intent of the state to ensure that the patient's advance directive is

^{*} Many of the state statutes were enacted at a time, two decades or more ago, when the possibility that hospitals and doctors would cut off life-preserving measures against the will of the patient was not even being discussed, let alone implemented. The laws were generally written in contemplation of the opposite situation, in which a patient or the patient's family might want to reject treatment, food, or fluids in circumstances in which the health care provider would wish to continue them. Today, according to Chuck Ceronsky, co-chairman of the ethics review committee of Minneapolis' Fairview University, "The right-to-die families find a more receptive audience in the hospital, as opposed to years ago when a doctor might say, My job is not to end life." Quoted in Pam Belluck, "Even as Doctors Say Enough, Families Fight to Prolong Life," *N.Y. Times*, Mar. 27, 2005. According to Dr. Lachlan Forrow, director of ethics programs at Boston's Beth Israel Deaconess Medical Center, "About 15 years ago, at least 80 percent of the cases were right-to-die kinds of cases. Today, it's more like at least 80 percent of the cases are the other direction: family members who are pushing for continued or more aggressive life support and doctors and nurses who think that that's wrong." *Id.*

⁺ Arizona, Indiana, Rhode Island, Utah, and the District of Columbia.

followed, since the right of the unwilling health care provider to deny life-preserving measures is coupled with the duty to find a provider willing and able to follow the advance directive. On the other hand, the statutes do clearly give the unwilling provider the right to refuse, and they specify nothing about life-preserving measures pending transfer.

Six states* require an unwilling health care provider to give "continuing care" to a patient pending the patient's transfer to a health care provider. While it might be argued that this means the patient must be given desired life-preserving measures while awaiting transfer, it is far from certain that it would be construed in this way by a court. The "care" that must "continue" is not defined. Hospitals unwilling to provide directed life-saving measures would argue that this does not mean they refuse to give "care" to the patient – they may provide palliative care, pain medication, and the like. It is also unclear what limit the word "continuing" may put on the obligation to give care pending transfer. Even if, for example, a hospital were to continue a ventilator the patient was already on, it might contend it has no obligation to provide *new* care – such as antibiotics if the patient develops an infection or CPR if the patient goes into cardio-pulmonary arrest.

Similarly, Colorado creates only "the duty to provide for the care and comfort of the [patient] pending transfer."²²

Two states – Delaware and South Dakota – specify a duty to provide directed treatment, nutrition and hydration or life sustaining care pending transfer, but immunize health care providers for any violation of the act that is in accordance with "reasonable medical standards" or "generally accepted health-care standards." Given the profusion of articles in medical and bioethical journals that support involuntary denial of life-preserving measures on quality of life grounds, together with the pervasive prevalence of "futility protocols" at so many hospitals, it is not unlikely that a health care provider who refused to provide life-preserving measures pending transfer would be able to maintain the refusal was in accord with accepted medical standards.

Missouri is a special case. Under its law, a health care facility may refuse to provide directed life-preserving measures pursuant to its "sincerely held moral convictions," but only if the facility had not "received a copy of the durable power of attorney for health care prior to commencing the current series of treatments or current confinement."²³ On the other hand, an individual physician or other health care professional who does not wish to comply has only the standard obligation of taking "reasonable steps" to transfer.

2 Laws with Time Limits for Life-Preserving Measures. Two states require that unwilling health care providers give the life-preserving measures chosen in advance directives pending transfer of the patient to a willing health care provider, but establish time limits by which a successful transfer must be arranged and authorize denial of treatment, food or fluids if the

* Alaska, California, Hawaii, Maine, Mississippi, and New Mexico.

time runs out. Virginia allows 14 days to arrange a transfer while life-preserving measures are provided. Texas allows 10 days, with a possible extension by court order if it can be shown there is a reasonable expectation that a willing provider will be found if there is an extension.²⁴

10 Protective Laws. Only ten states^{*} have laws that essentially protect the choice of a patient whose advance directive specifies that life-preserving measures should be provided in circumstances in which the doctor, hospital or other health care provider disagrees. Typically, the statutes in these states allow the unwilling health care provider to transfer the patient to a provider willing to comply with the patient's advance directive *but require that life-sustaining care be provided until the transfer can be completed.* For example, the Oklahoma law provides, "[I]f the physician or other health care provider refuses to comply with a medical treatment decision made by or on behalf of the patient ... , and if the refusal would in reasonable medical judgment be likely to result in the death of the patient, then the physician or other health care provider must comply with the medical treatment decision pending the completion of the transfer of the patient to a physician or health care provider willing to comply with the decision."²⁵ Under such laws, the choices of patients will be respected[^] unless the requested measures are physiologically futile.[^]

^{*} Alaska, California, Hawaii, Maine, Mississippi, and New Mexico.

[^] Even in these states there may not be an absolute guarantee that the wishes of the patient will be respected, as the case of Barbara Howe illustrates. The Massachusetts law, which we include in the protective category, provides, "If the facility or the agent ... is unable to arrange ... a transfer [to a willing provider], the facility shall seek judicial guidance or honor the agent's decision." Mass. Ann. Laws ch. 210D §15 (Law. Co-op. 2005). (New York has a similar option of resort to court.) Barbara Howe is a woman with Lou Gehrig's disease who made clear that she wanted a ventilator, and her daughter, who holds her health care proxy, has fought to maintain it against the wishes of Massachusetts General Hospital, which has argued that it should be terminated so that she dies. Ultimately, "judicial guidance" was sought. Nurses verified that Howe "wanted everything done to maintain her; including CPR, antibiotics, and ICU." While Probate and Family Court Judge John M. Smoot initially ruled in favor of the daughter's right to carry out her mother's wishes for treatment, in Spring 2004 he directed the daughter not to focus on her mother's wishes but on her "best interests" and recently brokered an agreement to terminate the ventilator so that Howe dies by June 30, 2005. Liz Kowalczyk, "Hospital, family agree to withdraw life support," *Boston Globe*, March 12, 2005.

[^]Under the Oklahoma law, for example, if the advance directive orders treatment the omission of which would not in reasonable medical judgment be likely to result in the death of the patient[^] then it need not be provided even pending transfer. If a particular treatment directed by the patient would not, in reasonable medical judgment, prevent or postpone death, then its denial would not "result" in the death of the patient.

Conclusion

Americans are being urged to set down their wishes concerning life-preserving medical treatment, food and fluids in advance directives to avoid the sort of debate over the wishes of a person no longer able to speak for herself that surrounded the case of Terri Schindler-Schiavo. To the extent those advance directives call for food, fluids, or life-preserving medical treatment in some or all circumstances, however, in the present state of medicine and the law there is no guarantee they will be honored in most states.

Endnotes

1. The exact poll question and results: A seriously ill patient has indicated that they want **food and fluids** but the doctor thinks the patient's quality of life is too low to merit food and fluids. Which of the following best describes your opinion: [ROTATE] the patient should be able to receive food and fluids or the doctor should be allowed to withhold food and fluids from the patient? [Number polled = 500; margin of error = +/- 4.5 %]

- 76% PATIENT SHOULD BE ABLE TO RECEIVE FOOD AND FLUIDS
- 14% DOCTOR SHOULD BE ALLOWED TO WITHHOLD FOOD AND FLUIDS
- 9% DO NOT KNOW/ DEPENDS/ NO BASIS TO JUDGE (VOLUNTEERED)
- 1% REFUSED (VOLUNTEERED)

2. A seriously ill patient has indicated that they want **life support**, but the doctor thinks the patient's quality of life is too low to merit life support. Which of the following best describes your opinion: [ROTATE] the patient should be able to receive life support or the doctor should be allowed to withhold life support from the patient? [Number polled = 500; Margin of error= +/- 4.5%]

- 77% PATIENT SHOULD BE ABLE TO RECEIVE LIFE SUPPORT
- 15% DOCTOR SHOULD BE ALLOWED TO WITHHOLD LIFE SUPPORT
- 7% DO NOT KNOW/ DEPENDS/ NO BASIS TO JUDGE (VOLUNTEERED)
- 1% REFUSED (VOLUNTEERED)

3. A seriously ill patient is unconscious and has never expressed a desire for or against **receiving food and fluids** should he or she require it. If the patient's family wants food and fluids for the patient, but the doctor thinks that the patient's quality of life is too low to merit food and fluids, which of the following best describes your opinion: [ROTATE] the family of the patient should be able to get food and fluids for the patient or the doctor should be allowed to withhold food and fluids from the patient? [Number polled= 500; Margin of error= +/- 4.5%]

- 72% FAMILY SHOULD BE ABLE TO GET FOOD AND FLUIDS FOR THE PATIENT
- 18% DOCTOR SHOULD BE ALLOWED TO WITHHOLD FOOD AND FLUIDS
- 9% DO NOT KNOW/ DEPENDS/ NO BASIS TO JUDGE (VOLUNTEERED)
- 1% REFUSED (VOLUNTEERED)

A seriously ill patient is unconscious and has never expressed a desire for or against life support should they require it. If the patient's family wants life support for the patient, but the doctor thinks that the patient's quality of life is too low to merit life support, which of the following best describes your opinion: [ROTATE] the family of the patient should be able to get life support for the patient or the doctor should be allowed to withhold life support from the patient? [N=500; Margin of error= +/- 4.5%]

- 74% FAMILY SHOULD BE ABLE TO GET LIFE SUPPORT FOR PATIENT
- 15% DOCTOR SHOULD BE ALLOWED TO WITHHOLD LIFE SUPPORT
- 9% DO NOT KNOW/ DEPENDS/ NO BASIS TO JUDGE (VOLUNTEERED)
- 1% REFUSED (VOLUNTEERED)

4. Karen Steinhauser et al., "Factors Considered Important at the End of Life by Patients, Family, Physicians and Other Care Providers," *Journal of the American Medical Association* 284 (2000): 2476, 2480.
5. Michael Jordan, *Durable Powers of Attorney and Health Care Directives*, 4th ed. (n.p.:West, 2004), preface & 2-2.
6. Quoted in Pam Belluck, "Even as Doctors Say Enough, Families Fight to Prolong Life," *N.Y. Times*, Mar. 27, 2005.
7. Lawrence Schneiderman and Alexander Morgan Capron. "How Can Futility Policies Contribute to Establishing Standards of Practice?" *Cambridge Quarterly of Healthcare Ethics* Vol. 9 (Fall 2000): pp. 524-531.
8. Ann Wlazelek, "Pendulum swings in life-saving efforts: Hospitals' policies on doing all they can to keep patients alive have changed," [Allentown, Penn.] *Morning Call*, June 13, 2004.
9. Alan Meisel & Kathy Cerminara, *The Right to Die: The Law of End-of-Life Decisionmaking*, 3rd ed.(New York: Aspen, 2004 & 2005 Supp.), §13.10 (Table 13.1, p. 13-44 to 13-46).
10. *Id.* at §13.09, p. 13-42.
11. Task Force on Ethics of the Society of Critical Care Medicine, "Consensus report on the ethics of foregoing life-sustaining treatments in the critically ill," *Critical Care Medicine* vol. 18, no. 12 (December 1990): pp. 1435, 1438.